

Illinois Department of Children and Family Services
Institutional Review Board Meeting
Minutes
September 22, 2020

ON PHONE

Dr. Margaret Scotellaro
Robin Albritton
Tammy Fuller
Arricka Newingham
Kim Mann
Rocell Cyrus
Janet Ahern
Brooke Taylor

EXCUSED

Robin Albritton
Janet Chandler

CALL TO ORDER

Janet Ahern called the meeting to order at 2:04 p.m. A quorum was present.

APPROVAL OF MINUTES

MOTION: Kim Mann made a motion to approve the minutes August 25, 2020.

Dr. Margaret Scotellaro seconded the motion and a unanimous vote from the remaining board members carried the motion.

FOLLOW UP

Marjorie Fujara. *Collaboration of Helpers Lowering Deaths of Children (Project: C.H.I.L.D.).*

Questions and concerns about their project. Questions sent to researcher and they responded. There are still concerns after they responded. With regards to allegations – similar to the egregious harm categories. Still need to identify which specific ones. Still need to address that.

The need for a data sharing agreement to figure out how that is going to work and they don't have a plan for that. Unable to assist with that. Data access is going to be a big issue. Starting on the outside and may not even know how best to do this. Is there someone who could support them on this – on DCP information in those counties. They need a lot more detailed information than what you can get via FOIA. Individuals want information from the database with no knowledge of how to use the database. Not their job to grab data for other people. What is their plan for acquiring and managing data.

Exactly what allegations are they wanting to know (use Tammy's email to do follow up questions to the researcher).

Notion should we think about issues of child abuse in a broader context and in order to do that, they are looking at specific data sets. They are replicating someone's model. The notion that we could potentially be more targeted, is not about agency providing a services to a county or community.

MOTION: Motion made to table the proposal.

NEW PROPOSALS

Stewart Goldman. *A Phase I Study of ABI-009 (NAB-RAPAMUCIN) (IND #133537) in Pediatric Patient with Recurrent or Refractory Solid Tumors including CNS Tumors as a Single Agent and in Combination with Temozolomide and Irinotecan*

Medical study out of Lurie Children's Hospital on brain tumours. Involves a specific child in our care that has had proton therapy in the past – needing a different type of therapy to treat his tumour. Child is getting a port on Friday. Want to begin treatment soon at Lurie's. They have worked very hard to get everything in to the IRB to be reviewed.

This is a phase I trial so this child doesn't have much in the way of other treatment options – has a recurrent brain tumour. A couple of other studies offered – this is the best with the least amount of side effects. Chemotherapy agents used. Has been studied in adults and has the same side effects. Serious or life-threatening complications are possible, but rare. Treatment will be an IV infusion twice during a 21-day cycle along with the other two therapeutic agents, which are oral. Just looking at the dose with which a child can tolerate it. Unknown as to what dose level the child will be assigned to. If he has a bunch of side effects, the dose can be reduced. No concerns about the study. Goals are not cure, hoping to show some effect on the tumour and give him more time.

Consultation attended by DCFS staff and others. If we approve it, Janet has asked that the letter be sent immediately so that we can start treatment soon. Child has only been in care for a month or so.

MOTION: Dr. Margaret Scotellaro motioned to approve the proposal.

Kim Mann seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

Julia Pryce. *First Star Scholars Evaluation Study -- AMENDMENT.*

Wants to look at the role of positive adult figures to students in the program. Recruited as freshmen and stay together for several years.

Changing some things due to COVID and changes due to supportive adult.

Not many changes from the original proposal.

MOTION: Rocell Cyrus motioned to approve the proposal.

Arricka Newingham seconded the proposed motion and a unanimous vote from the remaining board members carried the motion.

Julianna Wesolowski. *The Early Mental Health Program: A Multicomponent Treatment Framework to Address Severe Emotional Disturbance in Children.*

This is from Children's Research Triangle. They have a program where they work with emotionally disturbed children. Going to use children that are involved in their programs and they are proposed that they are going to decrease some form of trauma symptoms by going through their program (by a large percentage). Unsure of who pays for this. Think that they took Medicaid, unsure that they take YouthCare. Concerns about the cost of the program.

Ton of measures which are very classic measures – really high target at 80%. Not clear about the actual intervention – is it their packet of interventions or what is it that comprises their mental health program?

They have funding from SAMSA.

A little concerned about what is involved. Structure is based on coordinated specialty care. It's kind of vague. They will offer step parent education and screening. It's individual therapy. The entire package of the intervention results in change. There is no comparison group.

Are these deliverables that were required from the grant?

This isn't just for youth in care. How are the youth in care being identified? They would need guardian's consent.

Confused about the flow of identification and recruitment for the youth in care.

There is nothing in this proposal that was alarming or of concern. Not doing anything that was outside of typical research protocol practice. Youth get \$10 incentive (is that for youth and their parents, it doesn't specify). Questions about what they were doing, but no concerns.

They don't need data – because they are using their own. They want to collect a lot of data. Probably a benefit as they will be getting a bucket of treatments.

MOTION: Tammy Fuller motioned to approve the proposal.

Arricka Newingham seconded the proposed motion and a unanimous vote from the remaining board members carried the motion

OTHER:

Addition of Robin LaSota to the IRB. No concerns. Brooke will draft the letter for the Director's signature.

Next meeting re-scheduled for October 27, 2020 at 2 PM.

The meeting adjourned at 2:56 p.m.